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Predictors of psychosocial adaptation in children with CHD

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Original Article

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Abstract

Survival of CHD has significantly improved, but children with CHD remain susceptible to neurodevelopmental and psychosocial impairments. Our goal was to investigate the association between socio-demographic factors and psychosocial adaptation for future intervention. A retrospective cross-sectional study of an independent children's hospital's records was conducted. Psychosocial adaptation was measured by the Pediatric Cardiac Quality of Life Inventory Psychosocial Impact score (range 0–50, higher score indicates greater psychosocial adaptation). Bivariate and regression analyses were performed to estimate relationships between Psychosocial Impact score and socio-demographic variables including Child Opportunity Index, family support, financial support, academic support, and extracurricular activities. A total of 159 patients were included. Compared to patients in high opportunity neighbourhoods, patients in low opportunity neighbourhoods had a 9.27 (95% confidence interval [−17.15, −1.40], $p = 0.021$) point lower Psychosocial Impact score, whereas patients in moderate opportunity neighbourhoods had a 15.30 (95% confidence interval [−25.38, −5.22], $p = 0.003$) point lower Psychosocial Impact score. Compared to patients with adequate family support, those with limited support had a 6.23 point (95% confidence interval [−11.82, −0.643], $p = 0.029$) lower Psychosocial Impact score. Patients in moderate opportunity neighbourhoods had a higher Psychosocial Impact score by 11.80 (95% confidence interval [1.68, 21.91], $p = 0.022$) when they also had adequate family support compared to those with limited family support. Our findings indicate that among children with CHD, psychosocial adaptation is significantly impacted by neighbourhood resources and family support structures. These findings identify possible modifiable and protective factors to improve psychosocial adaptation in this vulnerable population.

CHD is the most common congenital defect in children, occurring in eight in every one-thousand live births.[1] In recent decades, numerous factors including improvements in cardiac surgery techniques, early diagnosis, and improved neonatal intensive care have increased the lifespan of children with CHD.[2] However, children with CHD remain susceptible to neurodevelopmental, psychological, and social impairments that affect quality of life.[3] For example, a study by Majnemer et al found that in a cohort of five-year-old children with a history of infant open-heart surgery, 20–22% had difficulty with self-care and social cognition, and 11–17% had functional limitations in socialisation, communication, adaptive behaviour, and daily living skills.[4] A systematic review by Latal et al found that a significant proportion of children with CHD experience psychological maladjustment compared with healthy controls, with reported rates ranging from 5 to 41%.[5]

Most research in children with CHD has focused on deficits in these areas, with a much smaller body of research focusing on factors that promote resilience and psychosocial adaptation.[3] Resilience has been defined as "the ability to recover and achieve psychosocial balance after adverse experiences".[6] One crucial component of resilience is psychosocial adaptation, which in children refers to the capacity to "feel good, respond adequately to the demands of the [home and school] environments, and achieve his or her objectives".[7] These traits have been found to positively impact psychosocial well-being, physical health, and development in patients with chronic illnesses.[8] Thus, an understanding of factors that predict resilience and psychosocial adaptation in various chronic illness populations may help inform intervention strategies.

While possible factors predicting resilience and psychosocial adaptation have been identified in families facing other chronic illnesses,[9–11] there is little research focusing on the CHD population. Given the adversity children with CHD face during their medical treatments, our

study's goal was to elucidate demographic and psychosocial factors that predict psychosocial adaptation in the CHD population, which may help inform and drive future intervention strategies to improve quality of life for these children.

Methods

Setting and data sources

We conducted a retrospective cross-sectional study at a dedicated cardiac neurodevelopmental program at an independent quaternary care children's hospital in Chicago, IL, using existing data collected during multidisciplinary visits, including both parent and child-reported survey data. Patients are eligible for referral to the cardiac neurodevelopmental program if they meet the American Heart Association high-risk criteria for developmental disorders or disabilities or if any developmental concerns are identified during cardiology follow-up. Active screening for eligibility is conducted prior to hospital discharge from the cardiac care unit and as a routine part of outpatient cardiology clinic intake. The cardiac neurodevelopmental clinic is composed of a cardiology provider, developmental-behavioural paediatrician, physical therapist, social worker, and education liaison. Referrals are made to additional services such as neuropsychology, mental health services, physical medicine and rehabilitation, neurology, and genetics as clinically indicated. As part of routine clinical care, a battery of patient and parent-proxy reported outcome assessments are administered, including the Pediatric Cardiac Quality of Life Inventory, a health-related quality of life questionnaire for children and adolescents with CHD.[1] For this study, child-reported measures included the Pediatric Cardiac Quality of Life Inventory, Child Version for 8–12-year-olds and the Adolescent Version for 13–18-year-olds.

Demographic and clinical data were collected from the electronic health record and patient and parent-proxy reported outcome assessment data was retrieved from the neurodevelopmental program's clinical database; these were then merged for analysis.

Study cohort

The inclusion criteria for this study included children who had received care through the school-aged cardiac neurodevelopmental program between June 2017 and May 2022 and fell within the age range of 8–18 years on the date of their initial visit. This age range corresponds to the period when the Pediatric Cardiac Quality of Life Inventory was routinely administered. Children without available data from the Pediatric Cardiac Quality of Life Inventory were excluded from the study.

Study variables

In our analysis, we incorporated both parent-reported and child-reported survey data whenever available. Each completed Pediatric Cardiac Quality of Life Inventory survey was recorded as an individual entry in our dataset, with a family identification number used to manage cases where both parent and child surveys were present. For patients with multiple questionnaire administrations due to serial follow-up visits, only the first administration was included.

The primary outcome variable under investigation was psychosocial adaptation, which we assessed using the Psychosocial Impact score on the Pediatric Cardiac Quality of Life Inventory. The Psychosocial Impact score is rated on a scale from 0 to 50, with higher scores indicating more favourable psychosocial adaptation. For the purposes of this study, we used the Psychosocial Impact score as an operationalised measure of psychosocial adaptation and assessed its association with potential predictors.

Specifically, we hypothesised that higher levels of financial and neighbourhood resources, in combination with robust academic and social support networks, would be predictive of higher Psychosocial Impact scores. The predictor variables included the Child Opportunity Index, which we derived using the Child Opportunity Index 2.0 database based on the child's permanent address as indicated in the electronic health record. Child Opportunity Index is a tool designed to assess and measure the quality of resources that support healthy child development within specific geographic areas or neighbourhoods.[12] We also explored the extent of family support, ascertained during a social work assessment conducted during the patient's initial visit to the cardiac neurodevelopmental program. Caregivers were asked to categorise their family support as "positive," "adequate," or "limited." In addition to these factors, we gathered supplementary social data, including the types of financial support, academic support plans (e.g., 504 plans, Individualized Education Plans), and participation in extracurricular activities (e.g., physical education classes, active play/backyard sports). These details were obtained during a social work assessment on the child's initial visit to the cardiac neurodevelopmental program. These data were retrieved from the electronic health record and categorised as predefined variables, with the option for "other" and the ability to provide free-text responses.

Moreover, this study integrated key socio-demographic information, including race, ethnicity, biological sex, and age.

Analysis

We performed univariate demographic statistics including age, reported sex, and race/ethnicity. Bivariate analyses included T-tests for differences in Psychosocial Impact score amongst socio-demographic variables.

Multivariable linear regression analyses were performed to estimate the relationship between Psychosocial Impact score and the following socio-demographic variables: Child Opportunity Index, family support, financial support, academic support, and extracurricular activities. In the regression analysis, we further categorised Child Opportunity Index into three groups: "high/very high," "moderate," and "low/very low," using the "high/very high" category as the reference group. For family support, we merged patients falling into the "positive" and "adequate" categories for the analysis. Financial support was categorised as "any government assistance" or "income only," while academic support was dichotomised as "any academic support" or "none noted." Similarly, extracurricular activities were dichotomised into "any extracurricular activity recorded" or "none." Regarding race/ethnicity, we categorised participants into four major groups to enhance sample size stratification: Non-Hispanic White, Any Hispanic/Latino, Non-Hispanic Black, and Non-Hispanic Asian or other race, with Non-Hispanic White as the reference group in the regression analysis.

Furthermore, we introduced interaction terms into the regression model. Interactions between financial assistance and Child Opportunity Index, as well as family support and Child Opportunity Index, were chosen to be included in the model given their main effects and theoretical relationship between the independent variables.

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Table 1. Child characteristics

Child Characteristics	n (%)
N =	159
Age at first visit to NCNP	
Mean (SD)	12 (3)
5–11 years	86 (54%)
≥12 years	73 (46%)
Biological sex	
Male	77 (46.5%)
Female	81 (52.8%)
Race	
White	64 (39.2%)
Hispanic/Latinx	61 (38.4%)
Black or African American	22 (14.8%)
Asian	8 (4.62%)
Other or not specified (left blank)	4 (2.97%)
Conditions/Diagnoses	
Septal defect	8
Pulmonary or systemic venous abnormality	3
Right heart lesion	16
Left heart lesion	6
Single ventricle	50
Transposition of the great arteries	19
Double outlet ventricle	11
Thoracic artery abnormality	6
Cardiac transplantation	20
Miscellaneous	3

Table shows key demographic statistics as well as CHD diagnoses for children included in the study.

All statistical analyses were conducted using IBM SPSS version 28.0, and statistical significance was defined as p-values less than 0.05.

Results

Patient characteristics

The initial sample size was 405 patients, of which 159 had associated Pediatric Cardiac Quality of Life Inventory data. A considerable number of patients lacked survey data due to the impact of the COVID-19 pandemic. During this period, clinic visits were conducted remotely through telemedicine, preventing the administration of surveys. Of the 159 patients who were included, 135 had child-reported surveys, 141 had parent-reported surveys, and 135 had both. The mean patient age was 12 years, 52.8% were female, and the group was racially diverse (Table 1). A diverse array of CHD types were included, the most common of which were single ventricle physiology (41% of patients), transposition of the great arteries (16% of patients), and right heart lesions (13% of patients). 13% of patients had undergone cardiac transplantation.

Table 2. Univariate analysis

Pediatric Cardiac Quality of Life Inventory respondent type	n	Median Psychosocial Impact score (IQR)
Child	92	34 (26–42)
Parent of child	94	33.5 (29–43)
Adolescent	45	36 (31–43.75)
Parent of adolescent	47	35 (28–42)

IQR = Interquartile range.

Levels of psychosocial adaptation

The median child-reported Psychosocial Impact score for the 8–12-year-old group was 34 (interquartile range 26–42); the median parent-reported score for this age group was 33.5 (interquartile range 29–43) (Table 2). The median child-reported Psychosocial Impact score for the 12–18-year-old group was 36 (interquartile range 31–43.75); the median parent-reported score for this age group was 35 (interquartile range 28–42).

Regression results

When comparing psychosocial impact scores between low, moderate, and high Child Opportunity Index neighbourhoods, there was an estimated 9.27-point lower score for patients living in low Child Opportunity Index neighbourhoods compared to patients in high Child Opportunity Index neighbourhoods (95% confidence interval [−17.15, −1.40], p = 0.021) (Table 3). Patients in moderate Child Opportunity Index neighbourhoods had a 15.30-point higher Psychosocial Impact score compared to high Child Opportunity Index neighbourhoods (95% confidence interval [−25.38, −5.22], p = 0.003). When compared to patients with adequate family support, those with limited family support had a lower Psychosocial Impact score by 6.23 points (95% confidence interval [−11.82, −0.643], p = 0.029). Variable interaction further modified these associations; patients with moderate Child Opportunity Index group had a higher Psychosocial Impact score by 11.80 (95% confidence interval [1.68, 21.91], p = 0.022) when they also had adequate family support compared to those with limited family support.

There were no significant associations between Psychosocial Impact score and financial support, academic support, or extracurricular activities.

Discussion

Our findings indicate that among children with CHD, child and parent report of psychosocial adaptation are significantly impacted by environmental factors, including neighbourhood resources and family support structures. Our findings are consistent with previous studies, which have found significant associations between access to community resources, social support, and improved outcomes in various chronic disease populations.[9,13,14] While psychosocial adaptation is just one aspect of resilience, this work provides important insights specific to children with CHD, as well as possible modifiable and protective factors to improve the psychosocial adaptation of the CHD population.

Our research did reveal an unexpected result: patients residing in moderate opportunity neighbourhoods exhibited a

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Table 3. Linear regression showing effect of socio-demographic variables on Psychosocial Impact score and variable interactions

Coefficients[a]									
		Unstandardized coefficients		Standardized coefficients			95.0% Confidence Interval for B		Collinearity statistics	
Model		B	Std. Error	Beta	t	Sig.	Lower bound	Upper bound	Tolerance	VIF
1	(Constant)	44.987	3.204		14.042	<0.001	38.676	51.298		
	COI Moderate	**−15.300**	**5.115**	**−0.644**	**−2.991**	**0.003**	**−25.375**	**−5.224**	**0.079**	**12.665**
	COI Low/Very Low	**−9.274**	**3.999**	**−0.424**	**−2.319**	**0.021**	**−17.153**	**−1.396**	**0.110**	**9.120**
	Hispanic/Latinx	−0.570	1.573	−0.028	−0.363	0.717	−3.668	2.528	0.605	1.652
	Non−Hispanic Black	−1.788	2.131	−0.062	−0.839	0.402	−5.986	2.410	0.667	1.499
	Asian or Other	−2.239	2.616	−0.056	−0.856	0.393	−7.393	2.914	0.842	1.187
	Academic Support	−2.068	1.500	−0.086	−1.378	0.169	−5.023	0.887	0.942	1.062
	Family Support	**−6.232**	**2.837**	**−0.219**	**−2.197**	**0.029**	**−11.821**	**−0.643**	**0.368**	**2.721**
	Extracurricular Activities	−1.928	1.380	−0.086	−1.398	0.163	−4.646	0.789	0.972	1.029
	Financial Assistance × COI High	−1.943	2.208	−0.059	−0.880	0.380	−6.292	2.405	0.804	1.244
	Financial Assistance × COI Moderate	−4.627	3.870	−0.086	−1.196	0.233	−12.251	2.996	0.704	1.421
	Financial Assistance × COI Low	4.410	2.369	0.150	1.862	0.064	−0.255	9.076	0.567	1.762
	Family Support × COI Moderate	**11.797**	**5.135**	**0.473**	**2.298**	**0.022**	**1.682**	**21.912**	**0.086**	**11.590**
	Family Support × COI Low	6.455	3.995	0.272	1.616	0.107	−1.414	14.324	0.129	7.725

$P < 0.05$ was considered significant and bolded below.
[a]Dependent variable: Reported Psychosocial Impact Score. COI = Childhood Opportunity Index; VIF = Variance Inflation Factor.

lower Psychosocial Impact score compared to those in low opportunity neighbourhoods. One possible explanation for this finding is that patients in low opportunity neighbourhoods may qualify for more support services that help alleviate the burden of living in a low-resource setting, while families in moderate opportunity neighbourhoods may not meet eligibility thresholds for additional support while still having unmet needs. However, a more in-depth investigation is needed to gain a better understanding of the factors influencing this disparity.

Possible intervention strategies to address the targets identified in this work include universal screening for community-based service needs and proactively linking families of children with CHD with existing community resources, such as educational programmes, recreational facilities like parks and playgrounds, extracurricular activities, and public transportation. A pertinent study by Moskoviz et al., focusing on patients with inflammatory bowel disease, demonstrated that the use of community-based resources, including educational programmes, recreational facilities, and condition-specific support services, was associated with improved post-surgery quality of life.[13] Our findings suggest that promoting awareness and ease of access to available community resources could similarly benefit the CHD population. These insights also underscore the urgency of broad, systemic change that ensures children, regardless of their socio-economic status or geographic location, receive equal access to opportunities and neighbourhood resources. Medical institutions with programmes serving children with CHD should consider these programmes as part of the care needed to ensure optimal long-term patient well-being.

Furthermore, identifying opportunities for bolstering social support systems may have a positive impact on a child's psychosocial adjustment and resilience. Prior research has demonstrated the advantages of robust social support networks for individuals managing chronic illnesses and their caregivers. For instance, a study conducted by Kroenke et al. revealed that among young women diagnosed with breast cancer, having larger social networks and greater social support was associated with enhanced post-diagnosis quality of life.[14] Another study, centred on caregivers of dementia patients, highlighted the significant influence of informal social support networks, including family, friends, and neighbours, in alleviating caregiver burden. This benefit was found to be independent of the receipt of formal support systems, such as the care-recipient's healthcare team.[15] Whether it involves biological family members, friends, neighbours, or the child's healthcare team, optimising the available support resources for families and children affected by CHD may substantially contribute to the child's psychosocial adaptation, even potentially mitigating the adverse effects of residing in low-resource neighbourhoods.

This study has several limitations. First, there is a presence of selection bias, as the cardiac neurodevelopmental clinic primarily receives referrals for the highest-risk patients. Furthermore, the accuracy of our socio-demographic data is limited by the reliability of the recorded information in the electronic health record. Additionally, the collection of survey data was hindered during the COVID-19 pandemic. Furthermore, it was not possible to obtain both child-reported and parent-reported survey results for every participant. For patients who had both child and parent-reported survey results, it is possible there were discrepancies between child and parent perceptions of the child's quality of life and psychosocial adaptation, which could lead to differing survey results for the same patient. Lastly, the precise definition of the

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term "resilience" is still debated, and while psychosocial adaptation is one component of resilience, it does not encompass all definitions of the construct. Future research should continue to focus on creating a single definition for resilience as well as developing specific tools to measure resilience in the paediatric population.

In summary, our study identifies significantly lower Psychosocial Impact scores for patients with CHD who reside in low and moderate Child Opportunity Index neighbourhoods compared to those in high-opportunity neighbourhoods. We also found that limited family support leads to lower Psychosocial Impact scores. Notably, patients residing in moderate Child Opportunity Index neighbourhoods experienced higher Psychosocial Impact scores when adequate family support was present. These findings underscore the impact of neighbourhood resources and social support on the psychosocial adaptation and resilience of children with CHD. Such insights present opportunities to enhance the psychosocial well-being of this vulnerable population through modifiable and protective measures.

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Competing interests. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the Federal Policy for the Protection of Human Subjects and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the Ann & Robert H. Lurie Children's Hospital of Chicago Institutional Review Board.

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